

Chapter 7: Losing It to Find It

Ninette

Being on a psychiatric ward for the first time ever, the first time around, that's a different experience in itself. The second admission I wasn't talking to anyone. I just wasn't talking. And the women on the ward there was like one or two, it was two of them, they were just coming for me. They made it uncomfortable for me to sit and eat in the dining area. They made it difficult for me to watch TV. They approached me several times threatening violence. I literally felt the full force of what being on a psychiatric ward is like the second time around.

And then I recall constantly being at the staff station outside the office door. That's where you like get things done, for example, if you want a phone charged or if you want to go out for a cigarette. And then I just remember always just being at that door and having members of staff just walk past me. Which is why, like, in my work on the ward I literally cannot do that. I cannot walk past people. I can't do it. Because what is stopping a member of staff of just saying, "What is it that you're after? Okay, give me a moment and then I'll help." Literally some, not all, were just walking past me like I was a ghost. So I literally started to feel that way. I started to feel invisible.

And that's when I started taking my writing really, really hard. I've still got that journal that I kept in there. I should have brought that, but, you know. Yeah, writing saved me. Writing and art. Yeah, the art therapist that was on the ward, I think, yeah, definitely played a part in helping me regain a sense of self. Because I felt like everything that I knew about myself was just like, I got it completely wrong. And that wasn't the truth. And if anything, even though I felt that way at the time, what I did I started the process of looking at the different things that made Ninette Ninette and then started picking and choosing the ones that actually helped me to feel better about myself. Writing, the art, and then gym. Ah gym saves me, saves my life. Yeah, but there wasn't any gym on site. So when I say gym, I mean, I was in my room, like, because I'm, I like boxing, so I was just like doing my own workouts, doing high-kicks, and I was just thinking if anyone approaches me on that level I want to be able to protect myself. Because I didn't feel protected by the staff at that point.

But no one ever, no one tried taking it to an extreme, where I'm talking about physical violence and that, I was able to defend myself as much as I could. And I think it was really, partially that experience of having to fend for myself that started to create, or recreate, that resilience within me that was always there. Yeah, the process of being alone with all of these different things going on around me reinforced the fact that I needed to regain my sense of self, my

independence, because I'm an independent person. So I just started working on myself.

Eve

So you were doing all these things to help yourself to explore what you were going through, the writing, the movement, the boxing, the jumping [Ninette laughs], the arts. Did, at any point, you chat to any of the clinicians about what was going on for you? About how you felt? Were you...

Ninette

I wasn't talking to them. I mean the only times where I was communicating with them was when they had what they call ward rounds. And then that's when the head either psychologist or what have you, when she would come around and make her *assessment* on you based on...

Eve

You're doing air quotes right now...

Ninette

Yeah, I am sorry! [laughs]

Eve

For the benefits of the recording.

Ninette

Usually, I'm really good at saying quote unquote but yeah I was. Like, OK to give an example of like the lack of support or the lack of communication. This same doctor, who was like the head of the department probably still is as well, and this was when I was leaving after the second admission. So they'd given my new care coordinator at the time was there, who was focused on there being cake in the room instead of the fact that this doctor had just upped my medication, didn't communicate to me about it, didn't communicate to my care coordinator about it, and literally I had to, this is when I started to feel a little bit more like myself, was like, "Hold on, why is this like this?" Why, this is when the muteness literally it had to fall at this point, I was like, "Why is this happening? Why have you changed this and not said anything about it?" And she had no words. She literally said nothing. We were sitting there in silence.

If it was a just sort of action that was warranted, why didn't she have anything to back up why she made that change? I mean, is there no control in these situations? Is the, quote unquote, patient not allowed to be like, "Hey, I'm not sure if I agree with that"? Why is the doctor even allowed to up the dosage just like that without consulting anyone? Like these little intricate details that come as part of my story, I think that's what requires the focus. Although it's seemingly negative, it's these little elements that build up a

wider puzzle to the things that are going wrong within the system. Which is why I knew I just had to come back. I had to come back. And if I could do, I would be working in that same hospital.

I went for a job, they offered it to me but the hours didn't work. But at some point I'm going to end up there. It's actually one of my things. I'm going to end up working there because it's not the only Trust that has issue. I'm sure all of the different NHS Trusts have their little things that are going wrong. But to have been on the other side of the counter or the other side of the office door and know firsthand of what these issues are, I have to go back. And it will happen [laughs]. It will. And rather than going in of the approach of, yeah, I remember how I was treated, it's more just, what can I do to help? What do you guys think the problem is? And let's come together and just work on getting it right. You know nothing's ever perfect, but if we come together with the right intention, anything is possible.

Eve

I'm seeing a picture of you in this encounter, sat with a psychiatrist, asking a question about your medication and not getting any response. What was that like?

Ninette

Same old same, Eve. Is it not on a par with the police that day, you know, their treatment of that? I've not received a response about that. I've not received an apology for that. My mum doesn't even acknowledge her part in what happened that day. What am I going to do about that? I can't do anything about that.

I can only really focus on the fact that I just want to be a part of the solution rather than the problem. And I feel like when I say problem, what I mean is people that are not willing to acknowledge their part in things. Or the fact that their role in things is actually making things worse. You know that kind of look at yourself. No filter. No nothing. Let's be honest. I've not received that. I've not received it in any way, shape or form. And that's perfectly fine. Because I've got no control over that. But I've got more control over myself [laughs]. I've definitely got control over myself. So why not just focus on that? Because I know I can make things happen. And with the right people, yourself included, we can make great things happen. But, some people are just set in their ways. And I'm not looking to tell people what to do but more show them there's a better way that we can do things.

Eve

Were there any conversations, moments, in this whole process for you, where you felt involved in decision-making about what happened to you? About your care? About medication? About any part of this process?

Ninette

There was. There was actually someone who listened to me and actually understood where I was coming from. And I've not mentioned them before, and it's so important for balance. So my care coordinator who left the organisation, and I've got no qualms with saying his name, I hope he doesn't mind me name dropping, his name's Joe Finlayson. Oh my gosh! I've never come across someone that's so dedicated to the work and actually took the time to listen to what it was I'd been through. Oh! He really did help. He used to come and visit me at home, we'd sit down, we'd talk about everything, and he'd just ask me, "What is it that you want to do? What things are going to help you feel more like you?"

So we just, we talked. We worked through things. But at this point I'd already got the list, you know? And that is not even a broad list, it's literally just three characters, which makes up the abbreviation of December, which is like my birth month, so it's diet, a decent diet, exercise and creativity. And he was like, "OK cool I understand this, but what specifically are we talking about?"

I'm like I need the gym in my life and I need help with, because at that time I was, I'd just turned vegan as well and I didn't really know what I was doing. Again I'm sure that plays a role in how I was perceived by others, but there you go. Yeah, we just worked through what each of those points actually looked and felt like and he helped me get there.

Joe helped me to get my paperwork together, because I wasn't even aware of the fact that I could get a copy of the notes of both of the situations that happened. And that was helpful to me, when I'd reached kind of like that beating myself up point, of looking over the notes and seeing what it was they were scribing down in their conversations about me rather than with me.

If anything the point that I'm trying to bring home here is, I hopefully have not come across as one sided in terms of always talking about this stuff that needs to be done. Yes, we know that. But there are people, like Joe, who really do make the difference. But unfortunately, he's left. He's left the NHS Trust overall and I don't think he'll be coming back.

So it's important for those people that are, I don't know, I think that it's kind of obvious sometimes when somebody really cares about something, or someone, or about their job. Those people need to be nurtured. We can't have any more people leaving like that.

I know a lot of work came independently and I had to sit with a lot of things that I'd been through, but having that type of support from someone that actually listened, invaluable. It'd be hard for me to think of what would have happened if Joe wasn't there. I couldn't even see it. I can't even see what that would have been like. So although there wasn't support for the main part

of the journey, when it did come in it was the right type of support, you know?

Eve

And that was when you were discharged the second time around you got some support?

Ninette

Yeah.

Eve

How long did that last?

Ninette

I think that lasted for just shy of three years. Because the service that Joe was with, they only really work with people for three years and then they kind of like free them off to fly by themselves. So yeah, it was just short of three years. Mmm, definitely made a difference. A positive difference. [laughs]

Eve

It's interesting because earlier on you were saying, "Oh, I couldn't have this conversation with a clinician?" These kind of things we're talking about, these tensions, the challenges around different understandings of insight, conceptualisations of insight, the way it plays out in human relationships. Where can that happen? You know, how can that be a part of the, I'm going to do quote unquote [laughs], "the system"? How do you think that can work?

Ninette

Listening. In short, listening. I mean I could drum up some long-winded explanation, but in short is it listening. Because why Joe was so effective is because he listened.

Whereas in comparison to my other experiences with like clinicians and doctors, they're really driven on, OK so I've got my knowledge, yeah, and we're going to do it my way. And that is that. And we're going to do things to you, rather than with you.

Which for me isn't effective. I don't know who that would be effective for. Maybe some people just need to be told what to do. But when it comes to your own care, how can someone be so authoritarian with it? It requires an encompassing conversation in order for things to move forward. How can you construct a "care plan", quote unquote, for someone, without asking them what they think they need? Does that make sense?

Eve

Yeah is that why when you were talking about the assessment, you were saying like "assessment" quote unquote?

Ninette

Yeah because the assessment that was taking place was more like a conversation had over my head. Obviously I was in the room, but they're having a conversation about me rather than with me.

I mean, if you like, let's step away from the mental health sort of arena side of things and just take it to friendships. If you were in a friendship with someone and the way that the other party was communicating with you was to talk about you, like behind your back, that friendship would not be sustainable.

So like, I'm not saying that, you know, in a psychiatric arena, that you know everyone there is your friend, that's not how it goes. They're there to help you. And of course you build a rapport with them that feels similar to a friendship. But it's not effective if you're talking over people rather than with them. People want to be included in their own care of course, no? They should have a say in it, it's their health [laughs] you know? People need to be included in their care. I think that's pretty straightforward, and it kind of bamboozles me that this is not the case.

If we take this to a more wider, outside of me, my work allows me to be giving insight on how much people feel that they're not being heard. And this is why I actually really love my work right now. Because what my role as a peer engagement facilitator is, is to go in and literally just sit down and listen to people. They can talk to me about whatever they like. Whatever they like, nothing is off the cards or off the table or too awkward.

And they tell me so much different things. And that's why I feel like I am in a privileged position to, to have people trust me with what they're going through and their bravery in even sharing it in the first place. Sometimes it takes a lot, especially being in a psychiatric environment. I mean, from personal experience I wouldn't want to be talking to anyone. But, there is something powerful in it I've learned now. There definitely is.

Eve

I made some notes when I was listening back to what you were talking about last time. So, yeah, you were talking about stepping up the love for yourself and having space in your heart and people having space in their heart to be helpful. And I'm interested in, well lots of things, like, how do you make the space? How do you maintain the space? How do you give the space some kind of boundaries, or safeguard the space so that things don't impinge on it, and reduce it or twist it, contort it in some ways? I'm really interested in this idea that you've put out there about making space in your heart for things.

Ninette

Gosh, you really were listening, weren't you? [laughs] OK, [reading Eve's notes] "The Angry Black Woman Who Has Lost It." Oh mate!

Eve

You talked about being grouped, grouped and boxed, and as I was listening I just put this box down. And you called it, the box, the process, "The Angry Black Woman Whose Lost It". And that really, really stood out to me as something that needs a lot more thought about how that narrative gets to be created, sustained, fed, watered. Like, how that comes about. And how we, as humans, do something about that, to challenge that.

Ninette

I've got the title, by the way. Just reading that out loud [clicks fingers] it's just come to me. "Losing It to Find It". What do you think?

Eve

Yes! I love this! You've got a title.

Ninette

Mmm hmm, yeah! Although it's just pinged [clicks fingers] into my head, because a lot of my things, I think that's why talking's important for me, although it's just kind of, ugh, I don't want to talk about myself, unless I know it's going to be helpful to someone. But essentially, I lost a lot. I lost a lot. I lost peace of mind, but then what I gained was like that sense of belonging, which I've never really felt in any of my jobs, or in life in general. But I really do feel like I am where I'm supposed to be in terms of work, my work in mental health, and the creative bits that I've got going on as well. But Losing It to Find It. So I lost the layers, but then I found some old and some new. Yeah, it's like the new and improved version of Ninette. A new recipe! [laughs] I need to stop making really rubbish jokes! It's funny to me, though. [laughs]

Eve

Losing It to Find It.

Ninette

Yeah. Do you like?

Eve

I do like it.

Ninette

Or do you think it can be improved in some way?

Eve

I really like it, because you were talking about these ends of a spectrum. The really dark and the difficult stuff, but how you've navigated your way through that. And you've done it, as you were talking about, you've done it pretty much by yourself, in some ways through creativity, through reflection, writing, finding out about your anaemia and how that can impact on your emotional wellbeing, that's a biggie.

Ninette

Because I don't think that my diagnosis is accurate in any way, shape or form. I don't think it speaks to me as a person at all. They could just say, "She was super low on iron", boof. Like, "She's got sickle cell trait anaemia", boof. And in the hospital, on both occasions, and they were taking a lot of blood from me, I can remember this because taking blood from me is literally like trying to get water out of a stone because my veins are really small, but yeah I remember them taking blood on several different occasions and none of them were able to come up with what it took me years to find out. You know, don't you think that's odd? I do.

But, in the same breath, I'm in some ways, I mean, happy isn't the word, I feel contented that I was able to go through that process of trial and error and trying new things and actually like, OK well I ate some greens today and I don't feel that bad anymore, you know? I think every person needs to have that sort of want to know themselves more. Or know when something isn't quite working right. But then it's also down to the doctors and the clinicians to bring in that hard founded knowledge to support things, no? These are rhetorical of course! [laughs]

Eve

Yeah I just wonder through a lot of this, the way that the physical, the mental, psychological, you know they're very separate in the system.

Ninette

But they're not separate entities though. The mental and the emotional, you say? And the physical. They're all connected. That, everything is connected in that arena of things. So why is it that, it feels as though clinicians and doctors are separating these things. I think it's a bit problematic, to say the least, but.

Eve

I wonder how many people go through physical stuff that has an impact on them emotionally but it takes years, maybe months, years, weeks, however long, it doesn't, you know, matter so much the time but that there is that delay in order to try and find out what's at the root, the cause of these difficulties...

Ninette

Listening is key. We can learn so much if we are able to just zip it. And the words that are flowing through the eardrums and what they could possibly mean. And if one doesn't understand, then that's when, you know, if the other party's able to welcome questions into the fold fair enough. But yeah, listening is so, I can't stress it any more, active listening.

Eve

If you could give the mental health system insight, what would it be?

Ninette

In regards to everything that I've been through, yeah? OK, what insight would I give them? That essentially, it's gonna cause more problems than it solves to do things the textbook way. What I mean about the textbook way is just like a one size fits all approach, you know? Because the symptoms or, yeah, the symptoms of a diagnosis and, no the symptoms of how somebody is acting, the behaviours of a person. OK let me just dial it down, dial it down. The behaviours of a person may speak to a particular diagnosis, but without taking the time to understand things like environmental factors, different things that make a person.

A diagnosis, for me, personally hasn't been useful. It's just created more confusion. So I guess the insight that I would give is that yes, some people, there may be, a diagnosis may be useful to some. However, without taking into consideration the context of an individual, kind of feel like it nullifies the diagnosis. So to try and keep it as brief and coherent as possible, I would say, yes, the clinician is important. I'm definitely not trying to, you know, brush aside the knowledge that they have, but the clinician alone isn't enough. It's definitely going to need a team of different people to underpin what an individual is about. To make an assessment on what support they need. So it's going to take more than one thing. And I think it just, it drives home the thing that I've been saying throughout.

And I hate to sound, I'm sorry if I sound repetitive, but the thing is, we all need to play a part in providing support for others. So yes, the clinician plays a role, but so does peer support, so does even the doctors as well. So we all need to be communicating. Let's say, a clinician, a peer support worker, and a psychologist, just for argument's sake, makes up a "team", quote unquote, then they all need to be communicating with each other so that they can build that insight into a person. And most importantly, they need to listen to the person in question. Because you might learn something that is going to help in your assessments and in your care plans. So clear communication and active listening. That's what I like to see more of [laughs]. That's all I want, you know? I think it's a simple ask, but, you know.

Eve

What does justice look like?

Ninette

For me? Justice is, throughout this process, I felt that justice has been served. Although I haven't had any apologies and I'm not waiting by the telephone for it. The justice has come in being able to express what has happened to me.

Because it's actually a really big deal for me that we're able to sit here and do this. Especially knowing that I've got this capability within me when I feel like I'm not being heard to just [clicks fingers] switch off. No words, no nothing.

So justice for me is actually giving people the space and the opportunity to talk openly and freely about things that have happened to them that are unjust.

